

HIV/AIDS

WORK GROUP ON HEALTH CARE ACCESS ISSUES for Hispanic Americans

Office of Minority Health
Resource Center
PO Box 37337
Washington, DC 20013-7337

WORK GROUP # 2
ACCESS TO RYAN WHITE SERVICES
BY HISPANIC AMERICANS

December 15 - 16, 1991



U.S. DEPARTMENT OF HEALTH & HUMAN SERVICE
Public Health Service
Health Resources and Services Administration
Bureau of Health Services Development
DHHS Publication No. HRSA RD-SP-93-8

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I. OVERVIEW

When the Congress of the United States enacted the Ryan White Comprehensive Resources Emergency (CARE) Act in 1990, the stated objective was

“...to provide grants to improve the quality and availability of care for individuals and families with HIV disease...”

The Ryan White programs make valuable services available to many people with HIV and AIDS. But availability of services does not necessarily mean that the people for whom services were designed are able to obtain access to them.

The Health Resources and Services Administration's Bureau of Health Resources Development (BHRD) administers Titles I and II of the Ryan White CARE Act. Part of BHRD's management concern relates to the barriers which may limit or prevent underserved populations from seeking access to available HIV/AIDS services.

In an effort to better understand the barriers that inhibit or, in some cases, prohibit these populations from seeking access to HIV services, BHRD convened a series of work group meetings beginning late in 1991. The goal of each work group meeting is to understand more about the real and perceived barriers faced by the under served populations in need of HIV/AIDS services. Based on work group recommendatinos, BHRD will develop evaluation projects that look at ways to improve the accessibility of HIV/AIDS services for the particular population. Technical assistance plans will also be developed to help States and cities implement effective program solutions. The results of the evaluation projects will provide an enhanced understanding of:

- why care may not be available to some populations
- why care is not sought or is not accessible when it is available, and

- what steps need to be taken to remove the barriers which limit or prohibit underserved populations from seeking services from Ryan White CARE funded programs.

Each work group has between 10 and 20 invited participants who are members of an ethnic or minority group. Participants include service providers, people living with AIDS, and health services researchers, some of whom are involved in the implementation of the CARE Act. Work group sessions are moderated by Federal staff.

The setting and format are informal to allow for creative thinking and in-depth discussion. The objective of the work group meetings is to assist BHRD in defining and understanding the complexity of issues which influence a person's perception about whether a service is accessible to them or not, and:

- to develop priorities for evaluation research and technical assistance on barriers to access, including topics, methods and designs; _to compile a bibliography on barriers to HIV/AIDS care and related health services research;
- to identify health services researchers working on HIV/AIDS related topics;
- to identify members of the affected population who directly deliver health care and support services and would serve as consultants to help identify issues of highest priority for evaluation and follow-up.

Areas for discussion included, but were not limited to:

- the barriers to access that are based on real or perceived patterns of discrimination;
- the patterns of referral, including lay referrals, self-treatment with "traditional/folk" remedies, "experimental" drugs, and reasons for choosing services/providers;
- the previous experience of people in need of care as a factor in their attitude about seeking care;
- the attitude and staffing of the provider agencies; _the organization and coordination of the many services and agencies a client uses, including CARE Act Title I planning councils and Title II consortia.
- the individual decision-making processes, including the medical, psycho-social, familial, and organizational factors.

The focus of group discussions is on describing the difficulties in accessing health care faced by individuals with HIV from particular populations, such as women or patients with ethnic, racial, economic or cultural backgrounds that differ from the population usually served by the agencies providing HIV services.

The goal is to modify the delivery system to make sure that Ryan White services are easily accessible by patients for whom the services are intended.

At least seven work groups on access to HIV services have been held or are planned through 1993 as follows:

- Work Group # 1 - African Americans
- Work Group # 2 - Hispanic Americans
- Work Group # 3 - Women
- Work Group # 4 - Native American Indians
- Work Group # 5 - Asian Americans
- Work Group # 6 - Gay Men (including gay men of color)
- Work Group # 7 - Evaluation Priorities and Strategies

Work Group meeting # 2 focused on access to Ryan White services by Hispanic Americans. BHRD invited Hispanic service delivery professionals and health services researchers with experience working in and with Hispanic communities, and people living with HIV to identify the barriers limiting Hispanic Americans from obtaining access to and participating in Ryan White HIV services. A Participants List is included in the Appendix.

The work group met on December 15-16, 1991 and was moderated by BHRD staff members Eda Valero-Figueira, Ph.D., Senior Public Health Analyst, Division of HIV Services, and Moses B. Pounds, Ph.D., a Senior Staff Fellow, Office of Science and Epidemiology. The work group's recommendations will be distributed for review and comment to the Title I and II CARE Act grantees and among the work group participants prior to the development of a final evaluation agenda. We view these work group meetings as the beginning of a learning and collaborative process among HRSA, its grantees, and the people with HIV disease.

The purpose of the following summary is to present the views of the work group members on the problems faced by Hispanic Americans in getting and maintaining access to HIV/AIDS services. The format of the meeting encouraged participants to discuss access issues and formulate evaluation and technical assistance questions which could be addressed by BHRD. This is a summary of the access issues discussed and program evaluation projects proposed by the work group participants over one-and-a-half days.

II. BACKGROUND INFORMATION

The U.S. Hispanic population constitutes approximately one-third of the total U.S. minority population. It is a rich and diverse mixture of Latin cultures each with its own heritage and nation of origin. While there are universal ties which bind the Hispanic community, such as a shared language and socioeconomic practices, the Hispanic American population is not monolithic and, thus, their health and social service needs must be met with diverse solutions.

Hispanics are the youngest and fastest growing major population group in the United States. The 22.35 million Hispanics make up 9 percent of the total U.S. population and are comprised of Mexican-Americans (63 percent), Puerto Ricans (11 percent), Cubans (5 percent) and Central and South Americans (14 percent)¹. The remaining 7 percent are Spanish-Mexican-Indians who live almost exclusively in the Southwestern U.S. It is expected that by the year 2000, Hispanics will represent the largest U.S. minority group. Some forecasts estimate that by the year 2010 the Hispanic population will increase to 31 million.

Geographically, 70 percent of Hispanic Americans are concentrated in six of the nation's most populous States - California, Texas, New York, Florida, New Jersey, and Illinois. Dr. Eli Ginzberg of Columbia University's Eisenhower Center for the Conservation of Human Resources, reported that:

"...the concentration (of Hispanics) in (these) six states indicates that the health policies of these states are first order determinants of the availability of health care to the Hispanic poor through their Medicaid programs, public hospitals, and special programs such as compensatory reimbursement to the providers of uncompensated care...."²

^{1/} Yzaguirre, Raul, "State of Hispanic America 1991: An Overview", February 1992, p.1.

^{2/} Ginzberg, Eli, Ph.D., "Access to Health Care for Hispanics", Journal of the American Medical Association, Jan. 9, 1991 - Vol. 265, No. 2, 238-241.

Although three-quarters of Hispanic families have achieved economic status above the poverty line, one in every four Hispanics and two of every five Hispanic children are poor. Hispanics are far more likely than other Americans to be among the working poor, but they are not likely to be covered by health insurance³. The 1990 Current Population Survey reports that in 1990, 32 percent of the U.S. Hispanic population were not covered by health insurance regardless of whether there was an adult worker in the family.⁴

AIDS has penetrated Hispanic communities with devastating consequences. Although Hispanics represent 9 percent of the total U.S. population, 16 percent of the AIDS cases reported to the Centers for Disease Control (CDC) through June 1992 are Hispanic American. The number of Hispanic people with AIDS has risen sharply since March 1988, from 8,000 to more than 37,000 cumulatively in June 1992.⁵ In New York City, for example, 40 percent of all AIDS patients under 13 years of age are Hispanic.

The Surgeon General of the U.S. Public Health Service, Dr. Antonia C. Novello, in a 1991 editorial published in the *Journal of the American Medical Association*, said:

"...The dynamic nature of Hispanic health issues requires an ongoing and responsive research capacity. Although significant strides have been made, particularly in the use of vital statistics, major new initiatives remain imperative."⁶

The Bureau of Health Resources Development, through the Work Group on Hispanics and Access to HIV Services, is responding to this imperative and is developing a program evaluation agenda which will lead to a better understanding of the barriers faced by Hispanic Americans seeking access to HIV and AIDS services, especially those services funded by the Ryan White CARE Act. The results of evaluation projects will be made available to providers of HIV and AIDS health and social service agencies, which will be encouraged to modify their service delivery systems to accommodate the special needs of Hispanic American patients.

^{3/} Yzaguirre, Raul, "State of Hispanic America 1991: An Overview", February, 1992, p.23.

^{4/} Ibid., p.23.

^{5/} "HIV/AIDS Surveillance - U.S. AIDS cases reported through June 1992", Centers for Disease Control, U.S. Department of Health and Human Services, p.9.

^{6/} Novello, Antonia C., MD, MPH; Wise, Paul, MD, MPH; Kleinman, Dushanka V., DDS, ScD; "Hispanic Health: Time for Data, Time for Action"; *Journal of the American Medical Association*, January 9, 1991 -Vol 265. No. 2, 253-254.

III. ACCESS ISSUES DISCUSSED

Hispanic Americans are confronted with many barriers which impede their ability to obtain adequate health care. The work group discussion identified several key factors associated with barriers to care, including the cultural background of the provider as well as serious financial and institutional barriers.

A. FINANCIAL

A patient's financial resources remain the most important factor in predicting the quality of health care received.^{7,8} Work group members described how financial barriers hamper an individual with HIV from seeking early treatment. Examples included ineligibility for health insurance because of pre-existing health conditions, sliding fee schedules pegged too high, and ineligibility for Medicaid benefits because of income which barely exceeded the income eligibility limit, or lack of residency/citizenship.

B. PARTICIPATION IN PUBLIC HEALTH CARE PROGRAMS

1. INSTITUTIONAL BARRIERS

Work group members reported that Hispanic American clients entering health care agencies bring expectations about how they will be treated that often conflict with those of the providers. They also bring heightened suspicions about the trustworthiness of the social service staff regarding the confidentiality of their diagnosis. Clients/patients report that they are treated impersonally and often disrespectfully by health care providers and staff members. Hispanic patients report that agencies care more about procedures and accuracy of information on forms than they do about a

7/ Ginzberg, Eli, PhD, "Access to Health Care for Hispanics", *Journal of the American Medical Association*, January 9, 1991 - Vol 265. No.2, 238.

8/ Hispanic Americans are more likely than Black or White Americans to be without health insurance coverage (32% of Hispanics, 13% of Whites and 20% of Blacks). This is accounted for by the large number of Hispanic Americans, frequently referred to as the working poor, who are the first generation in the United States and thus forced to seek low wage employment without health insurance benefits.

person's feelings or condition. While this is not unique to Hispanics, the chasm that exists between a patient's expectation and the behavior of health care providers further undermines the shallow confidence of people who feel sick, ill-at-ease, and unfamiliar with the English language. The resulting dissatisfaction with treatment is cited as contributing to delays in seeking treatment and the failure to comply with treatment regimens after treatment is provided.

Another institutional barrier to care is the limited amount of outreach that mainstream health facilities provide in Hispanic communities. This creates either real or perceived barriers to care and also may discourage participation in available programs. For example, the lack of waiting room literature in Spanish is perceived as sending a message that "this place is not for Latinos." The lack of services for an HIV/AIDS patient with multiple needs, such as drug treatment, pediatric and women's health services, and child care services, are additional barriers to Hispanics seeking health care.

Most Hispanics with HIV disease are not aware of the benefits of receiving early HIV treatment. In some cases, established counseling and testing sites have not informed the local population of the importance of receiving early treatment. If patients are not aware of early treatment benefits, they have little or no incentive to be tested. Media and communication campaigns are needed to explain the link between early HIV diagnosis and treatment that can delay the onset of AIDS.

2. ACCESS TO PLANNING AND DECISION-MAKING ARENAS

The participants identified several topics related to Hispanic communities gaining access to the decision-making process. Concerns arose about insufficient representation on local Ryan White planning councils from Hispanic community-based organizations or Hispanic people with HIV disease.

Some examples of this representation problem:

- planning council members with Hispanic surnames may lack knowledge of, or experience with, the HIV/AIDS issues; or
- expecting one Hispanic member to represent varied Hispanic subgroups within the community, rather than

appointing several individuals from each of those subgroups.

A related concern is how new Hispanic organizations are perceived by the more established AIDS service organizations (ASOs). For example, a community-based Hispanic organization was founded recently in a large city to respond to the needs of those at risk of contracting HIV and those already infected with HIV. This organization found it difficult to gain recognition from existing ASOs and medical institutions, which has made case management referrals difficult. Without such recognition and support, the Hispanic ASO found its legitimacy being questioned which resulted in its subsequent exclusion from the Ryan White planning council process.

The group discussed whether it is more effective to fund existing community based organizations (CBOs) to specifically serve the Hispanic HIV/AIDS population, or to fund only those CBOs which already provide HIV services to the Hispanic population.

3. GEOGRAPHIC BARRIERS

Location of HIV/AIDS services is a major factor in their accessibility. Services located in a familiar setting "close to home" are more easily accessible. But work-related migration — between States, regions, countries and between the mainland and Puerto Rico — poses additional geographic considerations and potential barriers. Many Hispanics use a variety of health care systems as they move between States and nations, making continuity of care and record keeping difficult.

The work group agreed that most people want health care close to their residence and in familiar facilities. However, the stigma of HIV/AIDS has introduced other considerations, such as quality of care and confidentiality. Quality HIV/AIDS care may be perceived as being available only "on the rich side of town" or in facilities with English-speaking staff. In these instances, people who have AIDS/HIV knowledge and/or are acculturated have the luxury of choosing to get their care in a culturally comfortable environment rather than dealing with a service agency that may consider them an outsider. Others, less comfortable in unfamiliar settings, will simply delay treatment rather than face the difficulties of negotiating their care with an agency unprepared to deal with their cultural needs.

Confidentiality is a significant concern for Hispanics in both city and rural areas and it can be complicated by geographic barriers. The work group gave examples of patients travelling across town, between rural towns, or from a rural town to a city in an attempt to keep their HIV disease confidential. However, continuity of care becomes an issue when patients are no longer able to make the trip to see the doctor and are forced to see local health care providers who may treat them but who do not have access to the patient's previous clinical information. This situation is improved if clients have a list of clinics that will serve them if they travel, move, or want to be treated closer or farther from home.

IV. AIDS IN PUERTO RICO

Participants familiar with Puerto Rico described important differences in the nature and scope of the HIV epidemic there. AIDS has disproportionately infected the Puerto Rican population⁹. To reduce the barriers to HIV care in Puerto Rico, specific attention must be paid to its distinctive geographic, political and sociocultural context. Service delivery solutions developed in U.S. mainland Hispanic communities are likely to fail if they are merely transplanted to Puerto Rican Island settings, especially if few adaptations are incorporated that address Puerto Rico's unique characteristics.

Further, coordination between AIDS programs on the Island of Puerto Rico and on the U.S. mainland is poor to non-existent. Given the extent of travel between the Island and the mainland, better access to care requires the development of systems of coordinated service.

Another important barrier to care is the work-related migration which occurs between Puerto Rico and the U.S. mainland. The most obvious problem is the difficulty of providing continuity of care to HIV/AIDS patients migrating between these locations. The most important factor in delivering quality care to those patients who must travel back and forth is the extent to which medical and case management services can be designed to accommodate the migration patterns.

^{9/} AIDS in Puerto Rico. National AIDS Commission. Washington, D.C.

V. CULTURAL VALUES AND BELIEFS

Hispanic culture is dynamic and complex, and is characterized by significant regional variations. Work group members noted that factors such as acculturation, migration and social isolation influence the behaviors of Hispanic people seeking health care. Hispanics may adopt some values, practices, and behaviors of the majority society while rejecting others. The group stressed the need for CARE providers to avoid stereotyping Hispanic cultures and to actively learn about and respect the distinctiveness of local Hispanic communities.

1. SPANISH LANGUAGE ISSUES

Work group participants noted that many Hispanic HIV/AIDS patients value communicating in Spanish, especially when discussing intimate and emotional matters such as illness and sex. Some patients hesitate to seek health care where Spanish is not spoken because they prefer to speak Spanish when describing their illness.

Confidentiality is a significant and pervasive issue. When trained and reliable translators are not available, there is a possibility that confidentiality will be breached. Hospitals have a tendency to use anyone who speaks Spanish without regard to their training. For example, physicians and nurses will sometimes call on Spanish-speaking hospital staff who have no health care training but happen to be in the clinic, such as janitors or food workers, to translate patient descriptions of symptoms and medical history. Language also poses a further barrier to obtaining access to HIV/AIDS services because Spanish-speaking people are frequently confronted with legal documentation and citizenship issues. Undocumented Hispanics are often afraid that entering the health care system will mean disclosure of their questionable citizenship status, which could result in deportation.

The benefits that accrue from retaining a bi-lingual health care staff may be negated if the clinic administrative staff, who are responsible for setting appointments or

completing admission forms, are monolingual. In the same way, patient linkages to support programs can be weakened. For example, eligibility requirements for State and Federal health and social programs may not be understood, or poorly communicated, or may seem difficult or impossible to meet. Difficulties also arise when the demand for Spanish-language services exceeds supply.

2. SEXUAL PRACTICES

Discussion about strategies to deliver effective treatment services to Hispanic Americans based on sexual identity revealed significant cultural factors and social norms that vary from region to region. For example, sex between men, while devalued by the larger Hispanic American community, takes place without necessarily being labeled as "gay" or "homosexual". On the U.S. mainland, Hispanic men who have sex with men are often isolated from gay communities or choose not to identify with groups organized around sexual identity. Creative efforts to increase effective service delivery for these men will require local assessments that focus on diverse behavioral patterns. Assessments will be difficult because these men, aware of local norms, may not readily step forward to express their needs.

3. CLINICAL TRIALS

Enhancing access to care through clinical trials remains problematic for some Hispanics. Experiences with previous clinical trials in Puerto Rico have led to perceptions among some Hispanics that patients are mistreated and their health care needs are neglected. Current clinical trials for people who are HIV positive have to continue to demonstrate their intent to improve participants' health and provide care for the multiple needs of patients.

4. DRUG USERS

HIV/AIDS service delivery issues related to Hispanic injection drug users (IDUs) are complex and poorly understood. Recognizing this, the work group focused on issues related to Hispanic American women among this group. Until recently, IDU/HIV programs have been oriented to men primarily. In the northeast U.S., where there is a high percentage of IDU women, AIDS services have not combined drug treatment with HIV/AIDS care in ways that meet the needs of women, particularly mothers. In addition, treatment environments frequently lack the safety and

privacy women need. Furthermore, some centers require women to surrender custody of their children. This often deters women from seeking treatment.

The participants described several AIDS prevention messages as culturally incompetent. Examples included messages which instruct women to encourage their IDU partners to use condoms. This is a risky message because a Hispanic woman suggesting the use of a condom (even though this is the eventual prevention goal) may cause the Hispanic male to suspect that she is being unfaithful or that she knows too much about sex. If the suspicion is strong enough, the Hispanic woman may risk physical or emotional abuse from the man. Such culturally unenlightened messages can undermine the reputation of a drug treatment program.

5. INDIGENOUS MEDICINE AND HEALERS

Health related beliefs and practices of some Hispanic patients often are not understood by care givers who have different cultural backgrounds. Hispanic patients may view biomedical¹⁰ (allopathic) medical practices as a direct threat to or in conflict with their cultural and/or religious beliefs. Some people prefer to use folk remedies at home or a curandero(a) (an indigenous healer) because traditional healers integrate cultural beliefs and practices and spiritual values into patient care.¹¹ Their approach is preferred, in part, because it treats the person as a whole being and within the context of the culture and society.

Participants also identified a negative aspect of using alternative therapies for those people who are also seeking biomedical care for HIV/AIDS. Biomedical providers often view indigenous healers and medicines with suspicion. They may ask patients to stop using other therapies before they will begin their treatment. Because of the real and/or perceived negative response, people who use indigenous healers and their medicines may not disclose this fact to biomedically trained physicians. Indeed, it is common for such individuals to delay seeking treatment from a biomedical physician until an emergency occurs.

^{10/} This term includes the licensed practices of physicians, nurses and physician assistants in hospitals and clinics. It contrasts with other medical systems and those based on culture.

^{11/} Estimates indicate that folk remedy varies and may be significant in some regions.

Participants emphasized that this is clearly a potential barrier against Hispanics taking part in clinical trials as well as in seeking routine HIV/AIDS care. The substances and practices used by indigenous healers, which are rarely documented, could have varying effects on the patient. The results could range from beneficial to injurious. Open minded biomedical providers can help patients evaluate indigenous therapies and thus help them to avoid the potentially injurious effects of some indigenous therapies.

VI. HEALTH CARE PROVIDERS

The role of health care providers as both barriers to and enhancers of access to HIV care services was a recurring theme throughout work group discussions. Participants focused their comments on two areas: shortage of Hispanic providers, and the shortage of culturally appropriate health care agencies, outside the Hispanic communities, which provide HIV/AIDS treatment resources.

1. SHORTAGE OF HEALTH PROVIDERS IN HISPANIC AMERICAN COMMUNITIES

Work Group participants cited the gap between large demand for HIV/AIDS services and the short supply in the six States with the largest Hispanic populations, as a major barrier faced by HIV positive Hispanics seeking care.¹² Many organizations serving Hispanic Americans find that the health care agencies they use are already overburdened with HIV/AIDS cases. HIV/AIDS is likely not to be the only concern of these agencies. Social service agencies must tend to the needs of many ethnic and minority groups as well as other urgent problems they are charged with managing.

While community outreach has been a successful strategy to draw people into care, it has also caused oversubscription in many service agencies. This has resulted in a major barrier to Hispanics receiving HIV/AIDS services because patients must wait weeks and months to see the doctor. Some simply give up; others forget the date of their appointment. Informal care givers, such as volunteers, community based organizations, and indigenous healers, partially meet the need for quality comprehensive HIV care but the demand still outstrips supply.

^{12/} Health Resources and Services Administration, "Health Care for Hispanic Individuals, Lewin/ICF. Washington, D.C., May 1991.

2. HEALTH PROVIDER TRAINING: CULTURAL AWARENESS BASED ON THE CULTURAL, SOCIAL, AND GEOGRAPHIC DIVERSITY OF THE HISPANIC AMERICAN POPULATION, PARTICIPANTS IDENTIFIED SEVERAL AREAS IN WHICH HEALTH PROVIDER TRAINING WAS LIKELY TO ENHANCE THE HISPANIC'S ACCESS TO CARE:

- Cultural awareness and cultural competence
- Knowledge of Hispanic communities,
- Cross-discipline training.

Building on their comments about the cultural, social, and geographic variations within Hispanic societies, the participants suggested that training for health providers must be considered an essential component of programs which seek to effectively increase the ability of Hispanics to obtain access to HIV/AIDS services. The group noted that many Hispanics have little or no choice if they want health services. It remains a fact, that to obtain health care Hispanics must usually travel to another community where it is likely that the providers will not understand their language or culture.

Because many health providers who currently provide services in Hispanic communities are not Hispanic or bi-culturally competent, there is a pressing need for training that would acquaint them with the culture of their clients, their client's needs, and techniques for effective communication. This training should include exercises to help providers become aware of ways their organization's policies and procedures could be adapted to accommodate the culture of the Hispanic community it serves.

3. HEALTH PROVIDER TRAINING: CAPACITY BUILDING

A related issue highlighted by the work group addressed cross-discipline training in the multiple diagnoses and treatment needs of individuals who may be HIV positive, IDUs, or have other health needs requiring care. Comprehensive care, increasingly the standard of care for HIV disease, is particularly important in ensuring that individuals seen for one condition receive care for other conditions as well.

Two types of cross-training emerged from comments and observations. The first type are training programs that strengthen the skills of Hispanic health and support service providers not currently working directly with HIV/AIDS.

The group noted that these Hispanic care providers need specific training about issues and problems that differentiate the HIV/AIDS patient from their routine patient population.

The second type of training is a cross-discipline training program for providers in agencies outside the Hispanic community to build their awareness of the culture of the Hispanic individuals with HIV/AIDS whom they will be treating or serving. For example, providers unfamiliar with the Hispanic culture may not understand how to interpret the reasons why a patient would miss an appointment or fail to take medication. Understanding each patient's cultural and social context is essential if a provider expects to be effective in delivering health care.

VII. RECOMMENDED EVALUATION STUDIES

The Work Group identified five areas for HRSA to consider for initial evaluation projects:

1. PARTICIPATION IN PLANNING COUNCILS/ CONSORTIA

Does a more representative and open planning council process result in increased access to Ryan White services by diverse populations?

Does involvement of Hispanic organizations on HIV planning councils result in (1) allocations which target care to Hispanic communities and (2) increased use of existing Hispanic medical, home care, housing, food, and other services?

Are planning councils which are representative of the Hispanic community they serve, more effective in filling the existing gaps in HIV services in that Hispanic community?

2. INTEGRATED/COMPREHENSIVE SERVICES

Does the availability of integrated and comprehensive HIV services (substance abuse treatment, women's health, mental health, children's care, housing, employment and legal services) increase access by the unserved and underserved?

3. INCREASING PATIENT SATISFACTION

Some Preliminary questions need to be answered:

- What is (are) the strongest determinant(s) of why Hispanic American patients do not use the health care system?
- What factors contribute to institutional avoidance?
- What causes patients to drop out of the medical care system?

Once the preliminary questions have been answered, follow-up questions need to be addressed such as :

- Is patient satisfaction and ease of access to care improved by a service delivery system that recognizes the

distinctive culture of Hispanics and responds to it appropriately?

- Is patient satisfaction and access to care improved when health care providers do not communicate judgment about their clients risk behaviors?
- Does delivery of care and treatment compliance improve in agencies that have addressed their organizational and management issues, such as resource allocation priorities, staff training, staff morale, and staff accountability? Does access to HIV services increase in agencies where Hispanics are in key positions in the health care facility? Do HIV service agencies that recognize and collaborate with patients who use alternative treatments and indigenous therapies have a higher percentage of treatment compliance?
- Does a culturally sensitive environment and the employment of providers from the same minority/ethnic groups increase patient utilization of the services?

4. ROLE OF INFORMAL COMMUNITY SUPPORT

Is access to care improved when informal community support facilitates or replaces biomedical care where appropriate (home care versus extended hospitalization or nursing home)? If informal care can adequately support or replace formal care, then funding training for families and other informal care givers should be provided.

5. EARLY TREATMENT

In Hispanic communities, does increasing HIV/AIDS knowledge and awareness of the benefits of early treatment result in HIV/AIDS patients seeking services? Analysis of this issue should be documented in many ways including regionally, among Hispanic men and women, among ID users, and among different economic groups. A different but related analysis needs to look at whether an accurate count of Hispanics with HIV infection has an impact on increasing the use of HIV services. The work group discussed the role that the public's perception of the HIV epidemic plays in a patient's understanding of the importance of early treatment. They noted that individuals who do not see themselves represented in the reported HIV statistics are often under the impression that they are not at risk and thus, will not be tested or seek early treatment.

WORKGROUP #2 - HISPANIC ACCESS TO HIV SERVICES
SELECTED ARTICLES

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13. Martin, Gerardo; Marin, Barbara, Vanoss, Perceived credibility of channels and sources of AIDS information among Hispanics, *AIDS Education and Prevention*, 1990, Vol. 2, No. 2.
14. Higginbotham, John C., MPH; Trevino, Fernando, M., Ph.D., MPH; Ray, Laura, A. MPA, Predictors findings from HHANES 1982-84, *American Journal of Public Health*, Dec. 1990, Vol. 80.

APPENDICES

Sunday Afternoon Session, 3:30 pm Hospitality Suite

- I. Welcome and Introductions of BHRD Director and federal staff - Moses B. Pounds, Ph.D.
- II. Introductions of Participants - Moses B. Pounds, Ph.D.
- III. Access and Ryan White CARE Act Projects - G. Stephen Bowen, M.D., M.P.H.
- IV. Evaluation Research and the Office of Science and Epidemiology - Katherine Marconi, Ph.D.
- V. General Discussion of Format for next day's work session

Agenda

Monday, December 16, 1991 **Marriott Suites**

9:00 - 9:15 am	Administrative and Procedural Matters
9:15 - 10:15 am	Access: Concepts and Definitions Getting to, Getting in and Getting treatment
10:15 - 10:30 am	Break
10:30 - 12:00 am	HIV, Hispanic/Latinos and Access <ul style="list-style-type: none">• What we know and don't know?• Issues: Generic and Specific
12:00 - 12:30 pm	Research and Evaluation Priorities: First Draft <ul style="list-style-type: none">• What do we want to know?• How do we investigate it?
12:30 - 1:30 pm	Lunch
1:45 - 2:45 pm	Research and Evaluation Priorities: Discussion
2:45 - 3:00 pm	Break
3:00 - 4:00 pm	Data, Methods and Strategies How to get answers to questions raised?
4:00 - 4:30 pm	Wrap-up
4:30 pm	Departure

Hispanic/Latino Access Work Group #2

Attendees

FRANK BEATTLE

National Council of La Raza
810 First Street, N.E., Suite 300
Washington, D.C. 2000
OFF:(202) 289-1380
FAX:(202) 289-8173

AMERICA BRACHO, M.D., M.P.H.

Radio America
500 Indian Trail
Anaheim, CA 92807
OFF:(714) 282-8300
FAX:(714) 282-8830

AIDA GIACHELLO, Ph.D.

University of Illinois at Chicago
Jane Addams School of Social Work
P.O. Box 4348 Mail Code 309
Chicago, IL 60680
OFF:(312) 996-9934
FAX:(312) 996-2770

JULIA HIDALGO, Sc.D.

Chief, Center for AIDS Services
AIDS Administration
Dept of Health & Mental Hygiene
201 West Preston Street
Baltimore, Maryland 21201
OFF:(410) 225-6755
FAX:(410) 333-5954

ADOLFO MATA

Program Development/Tech
Support Section
CDC, Mail Stop E-44
1600 Clifton Road
Atlanta, Georgia 30333
OFF: (404) 639-0826
FAX: (404) 639-0888

ANA A. POULIN

Hispanic AIDS Coalition, Inc. 4401
Lovejoy
Houston, Texas 77003
(713) 987-8372

JOSE TORO, Ph.D.

Executive Director
Fundacion SIDA
Apartado 36-4843
San Juan, P.R. 00936-4842 OFF:(809)
782-9600
FAX:(809) 782-1411

FRANK SALERNO

Terros Counseling Service
2830 West Landale
Peoria, AZ 85382
OFF:(602) 995-1371
FAX:(602) 995-8503

MARGARITA FIGUEROA

Project Director
South West Border AIDS COSSMHO
1501 16th St., N.W
Washington, D.C. 20036
OFF:(202) 387-5000
FAX (202) 797-4353

MERRILL SINGER, Ph.D.

Deputy Director for Research His-
panic Health Council
98 Cedar Street
Hartford, Connecticut 06106
OFF:(203) 527-0856
FAX:(203) 724-0437

Federal Participants

G. STEPHEN BOWEN, M.D., M.P.H.

Director Bureau of Health Resources
Development 5600 Fishers Lane,
Room 11-03 Rockville, Maryland
20857 OFF: (301) 443-1993

PATTY DELANEY

Ofc of Communication & IRM
Bureau of Health Resources
Development
5600 Fishers Lane, Room 9A-33
Rockville, Maryland 20857
OFF: (301) 443-6846

EDA VALERO-FIGUEIRA, Ph.D.

Division of HIV Services
Bureau of Health Resource
Development
5600 Fishers Lane, Room 9A-20
Rockville, Maryland 20857
OFF: (301) 443-6745

ISABEL FERNANDEZ, Ph.D.

Research Psychologist AIDS Program
National Institute of Mental Health
5600 Fishers Lane, Room 17C-06
Rockville, Maryland 20857
OFF: (301) 443-6100

ENRIQUE FERNANDEZ, M.D.

Chief, AIDS ETC Program
Bureau of Health Professions
5600 Fishers Lane, Room 4C03
Rockville, Maryland 20857
OFF: (301) 443-6364

MIGUEL GOMEZ

Division of HIV Services
Bureau of Health Resources
Development
5600 Fishers Lane, Room 9A-05
Rockville, Maryland 20857
OFF: (301) 443-6745

ERIC GOOSBY, M.D.

Director, Div of HIV Services
Bureau of Health Resources
Development
5600 Fishers Lane, Room 9A-05
Rockville, Maryland 20857
OFF: (301) 443-6745

KATHERINE MARCONI, PH.D.

Associate Director
Ofc of Science & Epidemiology
Bureau of Health Resources
Development
5600 Fishers Lane, Room 11-03
Rockville, Maryland 20857
OFF: (301) 443-6560

MOSES B. POUNDS, PH.D.

Senior Staff Fellow
Ofc of Science & Epidemiology
Bureau of Health Resources
Development
5600 Fishers Lane, Room 11-11
Rockville, Maryland 20857
OFF: (301) 443-6560

BOB SOLIZ

Division of HIV Services
Bureau of Health Resource
Development
5600 Fishers Lane, Room 9A-05
Rockville, Maryland 20857
OFF: (301) 443-6745



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